



**National Advocacy
Service**

For people with
disabilities

Annual Report 2023



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Foreword by Chairperson



Welcome to the 2023 Annual Report for the National Advocacy Service for People with Disabilities (NAS) and the Patient Advocacy Service. We are delighted to present this overview of our work, achievements, which highlights the positive impact independent advocacy has on people's lives to protect their human rights.

After three years, 2023 marked the official end of the COVID-19 pandemic. The issues associated with the pandemic, its restrictions and its disruptions to health and social services across the country disproportionately impacted people that access both our services. Some of the residual effects of the pandemic are still being felt by many of those living in residential and healthcare settings in 2023. Consequently, previous issues such as ongoing transfer delays and complaints regarding access to appropriate healthcare and housing persist.

2023 again demonstrated the significant need for our services as marked by another busy year for NAS. We were also pleased to welcome new board members Helen Brown, Melissa Byrne, Jacqueline Grogan, Tadhg Quill Manley, and Keiron Brennan.

In April 2023, The Assisted Decision-Making (Capacity) Act 2015 commenced. The Act aims to achieve key reforms including the abolition of the ward of court system for adults. A core principle of the Act is the presumption that everyone has capacity until proven otherwise. Equally, a person should be fully supported to make their own decisions in so far as possible, emphasising that a person's will and preferences must be considered at all times. Such principles equally underpin the work of Independent Advocates.

NAS has seen an increase in enquiries and cases over the course of 2023. Overall cases across NAS increased by 12.5% from last year highlighting the significant importance of and need for independent advocacy. NAS Advocates worked on a wide range of issues during 2023, including housing, issues relating to residential and healthcare settings, as well as supporting people to have their voices heard and their will and

Foreword by Chairperson

preference represented. NAS Advocates also saw a significant increase in cases related to decision-making as a result of the commencement of the ADM (Capacity) Act. Advocates provide essential support and underline the importance of individual human rights. Many of the barriers faced by those supported by both services severely impact a person's ability to live a meaningful life within their communities of choice.

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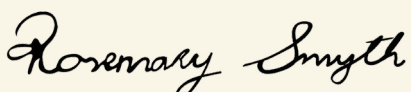
This year's Annual Report additionally highlights the significant growth in NAS advocacy issues relating to financial autonomy. Denial of financial autonomy and restrictions on people's finances limits their life choices. This will be highlighted in the forthcoming NAS social policy paper entitled: 'Examining the Barriers to Equal Access to Finances for People with Disabilities in line with their Human Rights'. This paper highlights the experiences of NAS Advocates and show the key role that independent advocacy plays in supporting people to realise their human rights.

NAS continues to operate under significant pressure and there was a large demand across the country for our service. In the past year, our waiting list remains persistently high, with 248 on the list at the end of 2023. Additional resources will be essential to secure the future ability of the service to meet the growing demand for advocacy.

This Annual Report is broken into two sections. Section one provides detailed information on all of the work carried out by NAS in 2023. Section two details similar information related to the Patient Advocacy Service.

Both Sections highlight key data around the number of enquiries received by our services, the number of cases worked on by our Advocates and the complexity of the cases we worked on. This document illustrates the wide range of people that we work with and the types of issues they face. Crucially, it provides an insight into how NAS Advocates work with people through several case examples.

I would like to express the Board's sincere gratitude to all the staff of NAS and the Patient Advocacy Service for their dedication and commitment to providing professional advocacy services throughout 2023. Finally, I would like to thank the Citizens Information Board for funding the essential services NAS provides to people with disabilities across the country.



Rosemary Smyth
Chairperson of NAS Board

What is NAS?



NAS is the National Advocacy Service for People with Disabilities. It is called NAS for short.



NAS works to protect the rights and choices of people with disabilities. NAS supports people with disabilities to have their voice heard.



NAS supports people with disabilities who may not have a lot of other supports or who may find it difficult to be a part of their community.



NAS supports people with disabilities including people who communicate in different ways.



The people who work for NAS to provide this support are called Advocates.

The Patient Advocacy Service





NAS also provides another important service called the Patient Advocacy Service.




The Patient Advocacy Service gives information and support to people who want to make a complaint about something that happened to them in hospital or a nursing home. They also help people after a patient safety incident.


Who Supports NAS?


 <p>Citizens Information Board information · advice · advocacy</p>	<p>The government gives money to the Citizens Information Board and then the Citizens Information Board gives this money to NAS.</p>
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	<p>NAS uses this money to fund its work.</p>
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Who Supports the Patient Advocacy Service?

 <p>Rialtas na hÉireann Government of Ireland</p>	<p>The Patient Advocacy Service is paid for by the Department of Health.</p>
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	<p>They give money to NAS to run the service</p>
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 <p>Patient Advocacy Service</p>	<p>The Patient Advocacy Service is an independent service. It does not get money from the HSE.</p>
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How NAS Advocates Work



NAS Advocates work alongside people with disabilities. They work out together what the person wants and make a plan called an advocacy plan.

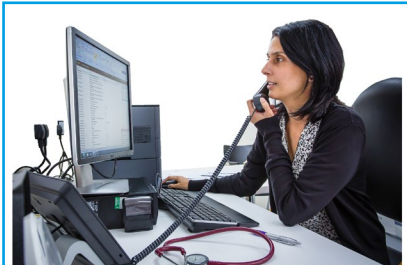


We all have different ways of showing what we want. NAS Advocates watch and learn the different ways people communicate.

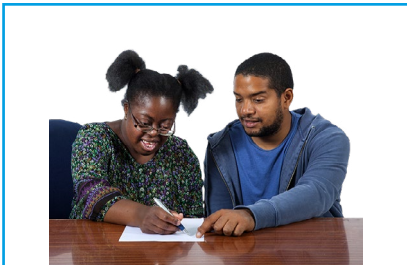


Advocates also talk to friends, family and staff to find out more about what the person wants.

How Patient Advocacy Service Advocates Work



The Patient Advocacy Service offers information, support, and guidance to a person about their issue or complaint. They also help people after a patient safety incident.



This is called empowerment advocacy.



Patient Advocacy Service Advocates also support people with their complaints and can attend meetings.

NAS Work in 2023



NAS Advocates worked on 1,775 advocacy cases in 2023. NAS waiting list ended 2023 at 248 from 250 in 2022.



NAS Advocates helped people speak up, write letters, make phone calls, attend meetings and think about important decisions.



NAS also provided information and full empowerment advocacy to 936 people in 2023.



NAS has a telephone number people can call for help with their issue on 0818 07 3000.



2,217 people called this number in 2023 up from 1,367 in 2022.

Patient Advocacy Service work in 2023



The Patient Advocacy Service provided support to 2012 people in 2023.



Advocates worked on 5617 complaint issues for the people they supported.



Advocates supported people to write letters, attend meetings and to speak up for themselves.



In November 2022, the Patient Advocacy Service began to support residents in private nursing homes. This continued in 2023



The Patient Advocacy Service has a website and it was visited by over 16612 new users in 2023.



The Patient Advocacy Service has a telephone number people can call for help with their issue on 0818 293003

Key Issues for NAS in 2023



NAS dealt with a lot of important issues for people with disabilities in 2023.



The biggest issues were around capacity building, housing, residential and healthcare settings, decision making, and financial issues.



NAS helped people with disabilities to work on these issues to try and make things better.

Key Issues for the Patient Advocacy Service in 2023



The Patient Advocacy Service worked on important issues for people in 2023.



The top complaint issues were people feeling their anxieties were not listened to, not being able to visit hospitals, questions not answered, hospital staff not communicating care plans to the patient and staff being rude.

Who Contacted Us?



NAS was contacted by people with many different types of disabilities. Some people had more than one disability.



Many people who were connected with NAS lived in residential services or attended day services.



People contacted NAS themselves or were supported by family, friends or support staff to be connected with an Advocate.



People contacted the Patient Advocacy Service in different ways such as themselves or through hospitals and nursing homes.

Other Important Work in 2023



NAS and the Patient Advocacy Service were members of groups that looked at important issues.



NAS and the Patient Advocacy Service also wrote papers called Policy Submissions. These were sent to the government and other expert groups.



NAS and the Patient Advocacy Service carried out a lot of work about the Assisted Decision Making (Capacity) Act and the Decision Support Service.



NAS managers spoke at important meetings about disability issues.

Telling People About Us



NAS and the Patient Advocacy Service took part in lots of events to talk about the work of the Advocates.



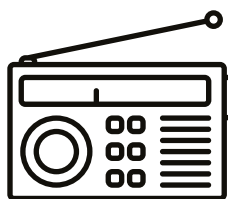
We told people how both services could support people with their advocacy issues.



We also used social media like Facebook and Twitter to tell people about work both services do.



The Patient Advocacy Service had two advertising campaigns in 2023.



This meant going on the radio to tell people about how they could support them.

NAS Highlights 2023

+3%
increase

NAS received **3125** new initial enquiries in 2023, an increase of **3%** from 2022 (3,021).

The average duration of an empowerment advocacy case¹ in 2023 was **4 months** and a representative case **18 months**, from start to finish.



NAS staff engaged in **198** promotional events and presentations in disability services and other services throughout Ireland. Due to waiting list numbers, promotional activities in our Southern and Midlands and Northeast regions have been curtailed.

+12.5%
increase

The total number of Active Cases in 2023 was **1775**, an **increase of 12.5%** on 2022, (1,577).

34,703
Actions

Advocates logged **34,703** individual actions on cases, spending on average 3 hours per closed empowerment case and nearly 32 hours per representative case.



The NAS website had **29,355 individual site visits** with 8,099 different users in 2023.

951

New Cases

NAS opened **951** new cases in 2023 of which **377** became representative type cases, a decrease of **7%** on 2022 newly opened cases.



The NAS national phone line received 2,217 calls in 2023.



Some of the biggest issues for people with disabilities which were worked on by NAS advocates in 2023 related to financial access, capacity building; housing and accommodation; issues within residential and healthcare settings; decision making and social care.

1. Empowerment advocacy supports a person to take action on their issue themselves. From a NAS perspective this may involve working with the person to explore fully what the issue is itself, suggesting some actions they may take to progress their situation, signposting them to various services (e.g. legal) or complaint mechanisms, providing a template letter, etc.

2. Vision, Mission and Values

Vision statement

Our vision for society is one where people with disabilities can exercise their rights – with dignity, autonomy, equality, and independence at the core. We recognise the capacity of people with disabilities to make their own decisions equally with others, in accordance with the United Nations Convention on the Rights of People with Disabilities (UNCRPD). We also recognise the right of all people to seek support, guidance and information when issues arise in relation to their care and treatment, which may lead to their wish to complain about their treatment or care or seek answers in the aftermath of a patient safety incident.

Mission statement

The National Advocacy Service for People with Disabilities (NAS) is a registered charity that provides an independent, confidential and free advocacy service that works exclusively for adults with disabilities. Our role is to work with those who may be isolated from their community of choice or mainstream society, may communicate differently and have limited informal or natural supports. We act as a catalyst for change through collaboration, capacity building and representation to make the rights of people with disabilities a reality. NAS also provides an independent, confidential and free Patient Advocacy Service, established in October 2019. The Patient Advocacy Service, which is funded by the Department of Health, is an independent, free and confidential Service that provides information and support to people who want to make a complaint about an experience they have had in a public acute hospital or nursing home, and in the aftermath of patient safety incidents.



Core Values

Our Strategic Plan 2018-2023 establishes the following five core values that underpin the work of NAS.

1. **Independence:** We work with the person independently of others and free from all conflicts of interest. The advocacy process is led and guided by the person.
2. **Autonomy:** We support the right of the person to self-direction/determination (i.e., to be in control of their own life) and to make informed decisions based on their will and preference. We also empower people to have their complaints processed in a balanced, fair and transparent manner.
3. **Equality/Citizenship:** We support the right of every person to assert and enjoy their human rights, to participate in society as an equal citizen and to fulfil their full potential within a life of their own choosing.
4. **Respect:** We work with the person in a way which demonstrates respect for the person as an individual and for their privacy, dignity and autonomy. All staff, partners and directors of NAS and the Patient Advocacy Service will act in a way that demonstrates respect for the people who use our services and each other.
5. **Empowerment:** We aim to facilitate the person to be an active participant in decisions which affect their life, through the way in which the advocacy process is carried out as well as the outcomes it seeks to achieve. We also aim to empower the person to make a complaint or engage with a review process and seek answers when things go wrong.



3. National Advocacy Service Remit

NAS provides an independent, confidential and free issues-based representative advocacy service. NAS is funded and supported by the Citizens Information Board (CIB) which has a mandate under the Citizens Information Act 2007 and Comhairle Act 2000 to support the provision of advocacy for people with disabilities. NAS operates on the principles that people with disabilities:

- **Make decisions about their lives.**
- **Access the supports they need to enable them to live their lives and enjoy meaningful participation in family, work and leisure.**
- **Are listened to and consulted by their families and those who provide their services.**
- **Can enjoy the benefits of participation in and contribution to their communities if they so choose.**

NAS has a particular remit to work with those who may be isolated from their community of choice or mainstream society, may communicate differently and those who have limited informal or natural supports. NAS advocates take affirmative action to uphold the person's rights, ensure fair and equal treatment and access to services. They make certain that decisions are taken with due consideration for their unique preferences and perspective. The work of advocates ranges from providing information and advice, to longer term full representative advocacy. Independent, representative advocacy is directed by the people who use it. It is person centred, accountable, accessible, impartial and independent of service providers, families, and other supports.



Case study:

Housing

Context:

Andrew is in his twenties and is autistic. He was residing in private rented accommodation, but the house was unsuitable to Andrew's health requirements. He raised the issues with his landlord several times. However, they remained unresolved, and Andrew's landlord informed him that he was going to be evicted. Unable to find alternative private rented accommodation, Andrew faced the prospect of becoming homeless. His life was heavily impacted by his living conditions and his mental health was deteriorating. Andrew contacted NAS, requesting support in liaising with his landlord and his local authority.

Actions by Advocate:

Andrew spoke to his Advocate about how worried he was, particularly at the prospect of becoming homeless. Andrew told his Advocate he felt his voice was not being heard by his landlord or the local authority. The Advocate created an advocacy plan with him, focusing on the main issues of concern; ensuring the local authority understood the impact Andrew's living conditions were having on his health and ensuring Andrew's voice was heard regarding his accommodation needs.

The Advocate explained the housing application process to Andrew, ensuring he was fully informed with the correct information. The Advocate spent time with Andrew, building his confidence and empowering him to write a letter to the local authority documenting his situation. The Advocate supported Andrew to attend meetings with the local authority where he was able to express his will and preference regarding his accommodation needs.



Andrew was offered a tenancy by the local authority, however, on viewing the accommodation it was unsuitable for his needs. He was distressed and felt pressured to accept the tenancy or face being homeless. After the Advocate helped Andrew to liaise with the local authority emphasising his accommodation requirements, they agreed to find him a suitable tenancy.

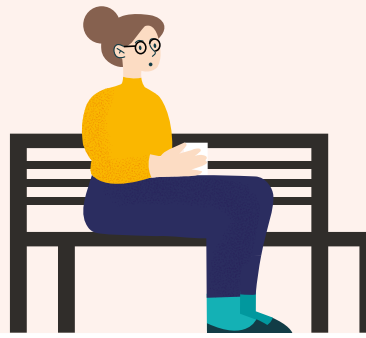
Outcome:

After some time and with ongoing support from his Advocate, Andrew was offered a suitable tenancy. He was very happy with the outcome as he knew the tenancy was secure and he was no longer at risk of homelessness. The Advocate signposted Andrew to various services in his new community, actively encouraging him to link in with those services to establish connections and prevent social isolation.

With the support of his Advocate, Andrew understands he can contact his local authority if he experiences any issues with his tenancy. Andrew told his Advocate that their support has built his sense of control over his own life.



Case study: Social Care



Context:

Jessica, and Irene are in their fifties. Both women have intellectual disabilities and have lived in the community with 24-hour staff support for many years. The Person in Charge (PIC) at the community house made an enquiry to NAS on behalf of Jessica and Irene, as they were inappropriately sharing a bedroom. Whilst the service acknowledged that the two women should not be sharing a room, they said there was no funding to move the women to either a larger house which would facilitate them having their own room or to extend the existing house to create additional bedrooms.

Actions by Advocate:

When the Advocate met both Jessica and Irene separately, they each individually expressed how difficult it was having to share the one bedroom. They told the Advocate that they each had different schedules which made sharing increasingly difficult for them and it was impacting their physical and mental health. They did however want to continue living in the house together if possible.

It was agreed that the Advocate would write to the service and make a complaint on behalf of Jessica. The Advocate also made a separate complaint on Irene's behalf. The Advocate met with the PIC and was informed that they had already brought the issue to management, who responded by stating there was no funding.

The PIC also informed the Advocate, that on a recent HIQA inspection, the inspector said the women should not continue to share the one bedroom. The Advocate agreed to write to the Regional Manager of the service and highlight the issues raised. The Advocate also wrote to HIQA informing them that the individuals continued to share the same bedroom despite recommendations to the contrary within the recent HIQA report. Following a long delay in providing updates, the service continued to say that it lacked funding and were applying for additional funds.

Outcome:

After some time, management informed Jessica and Irene and the Advocate that funding had been secured and that an extension would be built to accommodate an extra bedroom. Although the women needed to move out of their home for three months whilst renovations were ongoing, they were happy to move to nearby houses and were supported by staff they were familiar with.

Jessica and Irene invited the Advocate to come and see the extension before concluding their work. They no longer share a bedroom and are pleased to continue to share a home together, but now have their own rooms and privacy.



4. Our Service

4.1 National Advocacy Service Work in 2023

'It has been a pleasure working with you. It's my first experience of working with advocates for patients and I am delighted with how it has been such a positive experience for the patient and myself working with you. Thank you. You're doing such great work in your role, and I hope our paths cross again.'

Email from hospital social worker about working with a NAS Advocate in 2023.

NAS provides independent, confidential, and free professional representative advocacy to adults with disabilities throughout Ireland. The range of issues advocates support people to navigate continues to grow, both in numbers and complexity; 58 % of cases in 2023 had between 2 and 7 issues.

NAS aims to provide a high-quality advocacy service with a focus on continuous improvement. We measure the quality of the work we provide through regular case reviews and supervision, provision of regular team meetings, practice development sessions and formal training. NAS has a Code of Practice underpinned by a suite of policies to support our advocates in their work. These policies are regularly reviewed to ensure we stay up to date with best practices and knowledge.

NAS has identified that as our work has become more complex and is provided to more people, we need to increase our resources. This is most acute in locations where there are waiting lists for access to our service, but it is also needed across the country to ensure that as many people as possible with a disability who meet the criteria for our services have prompt access to advocacy.

The criteria for accessing NAS services are outlined in our access and eligibility criteria policy, which is an internal document used in NAS operations. The policy is designed to ensure that NAS can uphold its remit of providing advocacy services for people with disabilities. To access NAS services a person must meet the criteria outlined in this policy. The policy ensures that our resources are utilised most fairly and efficiently and that those who most need our service can access it. The document focuses on a range of relevant issues including quality of life, risk of harm to a person's health, issues accessing services, lack of natural supports, and some other factors.

The number of people on the waiting list to access NAS services went from 265 in January 2023 down to 248 at the end of December 2023, a reduction of only 17 people. While such a waiting list may look rather small when compared to waiting lists for other public services, behind these numbers lie individuals with disabilities who are facing significant barriers and who are experiencing personal suffering. These waiting lists are not distributed evenly across the country. Some counties have no waiting list whilst counties like Cork, Kildare, and Waterford may have a waiting list of up to 12 months or more, amounting to a postcode lottery. The lack of sufficient resources available to NAS to deliver its services is also making waiting list management both more difficult and more time-consuming.



There is a very clear trend of an increase in the overall number of cases each year – rising from 856 in 2017 to 1775 in 2023 (up from 1577 in 2022).

Despite an increase of over 50% in the number of enquiries and cases to the Service since 2015 there has been no increase in permanent Advocate numbers

Despite an increase of over 50% in the number of enquiries and cases to the Service since 2015 there has been no increase in permanent Advocate numbers. This means that people who are already isolated and in difficult situations are left waiting a long time for access to advocacy. Currently in the Southern Region, 94 cases on the waiting list have been waiting for independent advocacy for between 12 to 18 months. This translates into increased complexities as by the time an advocate works with the person, the issue has further escalated.

The importance of representative advocacy is underlined in the recommendation² to provide people with a statutory entitlement to independent advocacy in the Joint Committee on Disability Matters, the UNCRPD Budget 2023 Pre-Budget [Submission](#)³, and the importance of access to advocacy noted in the [Ombudsman's Wasted Lives report](#)⁴. It is also strenuously underlined in the ADM Codes of Practice.

NAS advocates help people in two ways, with full representative advocacy, and with empowerment or short-term advocacy and information support.



2. Point 4.4 of Joint Committee on Disability Matters Aligning Disability Funding with the United Nations Convention on the Rights of Persons with Disabilities Budget 2023 Pre-Budget Submission

3. https://data.oireachtas.ie/ie/oireachtas/committee/dail/33/joint_committee_on_disability_matters/reports/2023/2023-02-23_report-on-aligning-disability-services-with-the-united-nations-convention-on-the-rights-of-persons-with-disabilities_en.pdf

4. <https://www.ombudsman.ie/publications/reports/wasted-lives/OMBWastedLives2021.pdf>

NAS advocates are reporting systemic policy issues in housing, finances, and healthcare settings, with ongoing concerns about quality of life for those in congregated settings and restricted access to personal finances, highlighting critical areas for social policy work in 2023.

- Overall, NAS received a total of 3125 initial enquiries in 2023. This figure has grown by 3% since 2022, when there were 3,021 initial enquiries.
- NAS provided full representative advocacy to 839 people in 2023. This work involved extended engagement with individuals, ensuring that their will and preferences were heard, understood, and considered. It also involved writing correspondence, attending meetings with the person in a variety of settings, speaking up for the person and supporting them to self-advocate.
- Of the 839 full representative advocacy cases in 2023, 454 cases had been open from 2022, while 377 new cases were opened in 2023.
- There were a total number of 1775 open cases, an increase of 12.5% from 1,577 in 2022, (1,577) and 881 closed cases, an increase of 18% from 747 in the previous year.
- In addition, NAS also provided full empowerment support in a further 936 cases in 2023. These instances involved supporting individuals to self-advocate, through information provision and empowerment. It included one-off representations, such as writing a letter, information provision by phone, and short-term support. It also included signposting and supporting referrals to other services.
- Combining both ways that NAS advocates assist people, NAS provided advocacy support in 1755 cases in 2023. It should be noted that due to the complexity of cases growing, the higher number of advocacy issues results in these cases staying active for longer.
- NAS advocates are reporting systemic policy issues in the area of housing, finances and residential & healthcare settings. Ongoing admissions to nursing homes for those under 65 being reported. Compatibility issues across residential settings arising frequently. Ongoing concerns exist regarding quality-of-life issues for those living in congregated settings.
- A significant ongoing issue across our casework is people NAS supports not being able to access their own finances. This is a key area identified as a focus for social policy work by NAS for 2023.

4.2 Publication of Casebook

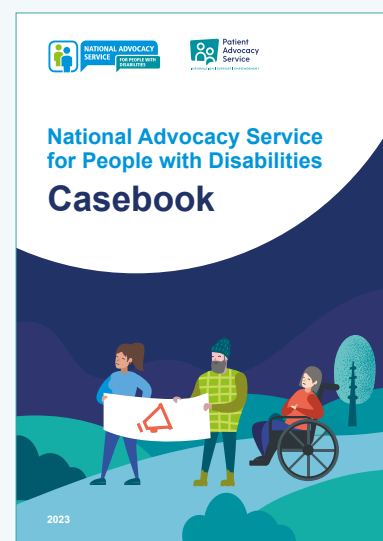
The Casebook provides a comprehensive overview of the crucial work undertaken by both services, highlighting the positive impact of independent advocacy on individuals' lives and the protection of their human rights.

NAS and the Patient Advocacy Service published our second joint [Casebook](#)⁵ document.

The Casebook provides a comprehensive overview of the crucial work undertaken by both services, highlighting the positive impact of independent advocacy on individuals' lives and the protection of their human rights.

The Casebook offers a unique glimpse into the diverse range of issues that both NAS and The Patient Advocacy Service supported people with in 2023. Each case example demonstrates how advocates in both services help bridge gaps in systems, ensure best practice across public services, promote positive systemic changes and show how independent advocacy has a positive impact both for individuals and in communities across Ireland. The Casebook covers topics such as access to justice, capacity building, parenting with a disability, housing, and healthcare and nursing home complaints.

In addition, 2023's casebook featured a collection of 'Access to Finance' cases from NAS, showcasing the increasing advocacy needs related to financial autonomy. Financial issues were a key issue across all NAS regions in 2023. The financial cases included in this year's Casebook are part of NAS's forthcoming social policy paper entitled "Shortchanged: Barriers to Financial Autonomy for people with disabilities in Ireland."⁶ This focus also incorporates an Easy-to-Read booklet to support people to understand their financial rights, one key topic that NAS will focus on in 2024.



5. www.advocacy.ie/app/uploads/2024/01/NAS-Casebook-2023-Final.pdf

6. www.advocacy.ie/app/uploads/2024/10/NAS-Social-Policy-Paper_final-web-1.pdf

4.3 The Assisted Decision Making (Capacity) Act 2015

The Assisted Decision-Making (ADM) (Capacity) Act came into effect on April 26, 2023. Between the commencement of the Act and the end of December 2023, NAS advocates supported 321 people on ADM advocacy cases.

The Act places an obligation on anyone interacting with a person, including a person with a disability, to presume they have the capacity to make their own decisions, to support their decision-making, to understand their right to make an unwise decision, and to intervene only where necessary and when it respects the person's rights, will and preference.

The ADM is critical to ensuring people have the right to make decisions about their personal welfare, property and affairs in accordance with their will and preference. The UNCRPD recognises that all people have the right to make decisions about their lives and the ADM now provides a vehicle for the implementation of such rights in law and everyday life. Importantly, it facilitates empowerment for all people to live with dignity and respect, and to progress their autonomy and their self-determination. Underpinning this, is also ensuring independent advocacy doesn't become diluted in the court process and remains fully person-centred and directed.

The commencement of the Act kickstarted the countdown of the three-year period within which people who are wards of court would be discharged from Wardship, with or without decision-making support. Wardship strips all decision-making rights from people, but the ADM will have a long-lasting and positive impact on people with disabilities to progress their autonomy and self-determination.

In the last quarter of 2023, decision-making matters made up a significant part of NAS casework. Since the Act came into effect, issues affecting people NAS supports varied from nursing home staff not acting in accordance with the ADM Guiding Principles to Do Not Attempt Cardiac Pulmonary Resuscitation (DNACPR) orders placed on people in hospitals and residential services without consent. Crucially, NAS advocates worked on 35 active Ward of Court cases during this period.

4.4 Complexity of NAS Work

The number of issues per advocacy case for NAS has continued to increase year on year. This continued to be the case in 2023, underscoring the multifaceted nature of the casework. Additionally, this impacts on the capacity of staff to provide support in such complex work. Cases with more than one issue can be particularly complicated as NAS advocates may have to coordinate communication with many stakeholders and agencies that have become involved in a person's life, all the while ensuring that each issue is worked through at a pace that works best for the person.

Complex issues can be interdependent. For example, in an access to justice case there can often be an impact on a person's housing or day service situation, which also requires advocacy support. Through advocacy plans, the complex work of advocates is managed and focused. Cases with individuals are closed when the issues in the advocacy plan are resolved.

The majority of NAS cases now have between 2 and 7 issues. The number of issues per case has also increased from 495 with 2-7 issues in 2018 to 1036 in 2023.



The increase in the number of issues per full, representative advocacy case is due to several factors:

Increased awareness of the United Nations Convention on the Rights of People with Disabilities (UNCRPD) among service providers.

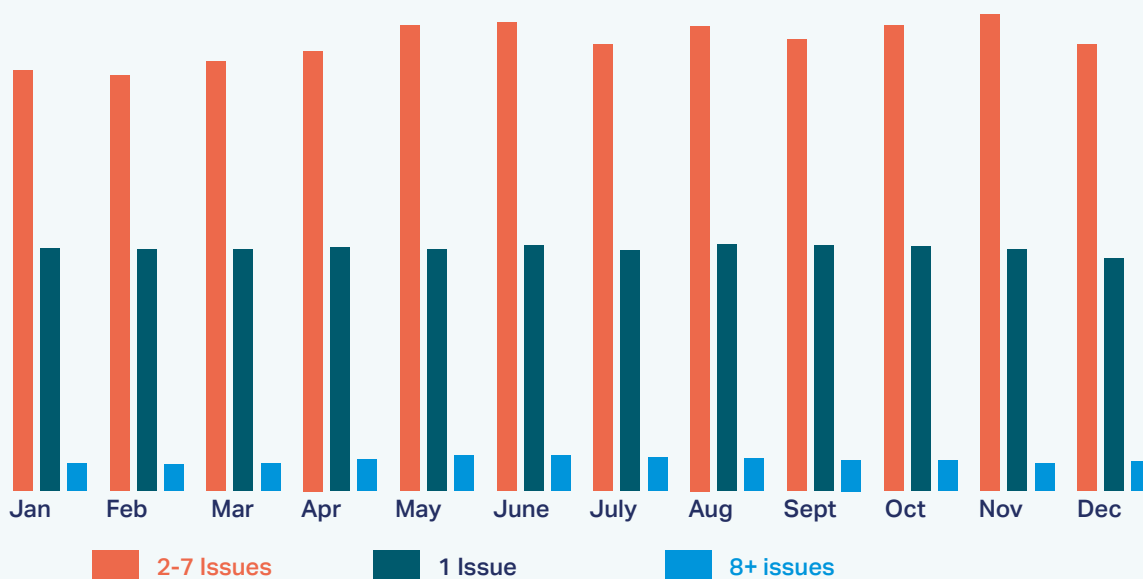
Increased awareness of future obligations on service providers because of the Assisted Decision Making (Capacity) Act 2015, which came into effect in April, 2023.

Embedding of HSE Safeguarding Policy.

Increased knowledge of NAS among disabled people and their representatives.

Increased knowledge and skills in NAS staff.

Number of advocacy issues per case (complexity)



In recognition of the fact that NAS casework has consistently grown in complexity, NAS developed a Complex Case Review Forum. This is a new method of reviewing and supporting particularly complex cases. It involves a meeting of several NAS staff from different roles, who are briefed on a complex anonymised case. Each staff member then pools their experiences, knowledge and expertise and provides possible options and pathways to progress cases.

4.5 Key Issues for NAS in 2023

Although the issues associated with delivering the NAS service in 2023 were similar to previous years, the residual detrimental impacts of Covid-19 evident in the previous three years throughout residential and healthcare settings has dissipated with the lifting of all restrictions. Despite this, many of the same issues persist, such as:

- Delayed transfers from residential settings.
- Slow progress on moving people from congregated settings.
- Dearth of accessible housing, particularly for under 65s and people with ABIs or physical disabilities, which has resulted in people languishing on waiting lists.
- Delays in assessment and provision of new home support and personal assistance services.
- Inappropriate housing or referrals made far from a person's community of choice.
- Lack of access to home support and personal assistant services due to insufficient numbers of staff in many service providers.

One of the most pressing emerging issues in NAS casework this year has been financial matters, making up 12% of all NAS casework in 2023. Many people with disabilities face barriers in relation to upholding their rights around personal finances; including setting up bank accounts, accessing bank accounts and bank statements, digital exclusion, having the freedom to exercise choice and control over financial decisions and issues of control and abuse by third parties including third party control of their Disability Allowance whereby individuals are given weekly pocket money instead of direct access to their own money. NAS has found that people with disabilities face multiple obstacles with basic banking tasks that often prevent them from exercising their autonomy to manage their own finances, which significantly impedes people's rights and quality of life. Equally, the move towards digitalisation in the banking sector has meant that online platforms, complex authentication requirements, a lack of accessible information, such as easy-to-read formats, and automated customer support all contribute to excluding people with disabilities from accessing their finances. There is an urgent need to overhaul the systemic barriers people with disabilities across Ireland face in accessing their own finances. As a result, NAS was allocated a grant by CIB to produce a social policy report on the issue of access to finances for people with disabilities. The report (to be published in 2024) outlines key recommendations in tackling these issues from third party control to discrimination and equality.

“The bank was due to close my account. I wanted to thank you for your assistance in getting my public services card to access their mobile banking unit, it proved to be extremely simple and fast. I also want to thank you for all your help with my passport. I don’t know how I would have gotten through all the bureaucracy. I was grateful for your informed support. Knowing I could call on you gave me the strength I needed to finally complete all my tasks, so thank you warmly and sincerely. Your service is invaluable and very necessary. With Gratitude.”

Email received by someone supported by NAS in 2023.

NAS advocates have also noted many people who are under-65 are still living in, and being placed in, nursing homes. They also have reported many other issues associated with living in these settings which are continuing to occur, including compatibility issues with other residents, not having autonomy over their own lives and not being able to access their own money and communities, etc. Additionally, they are often the youngest resident by decades, experience very little stimulation, see coffins pass by their bedroom door on a regular basis and have virtually no money after fair deal and nursing home charges.

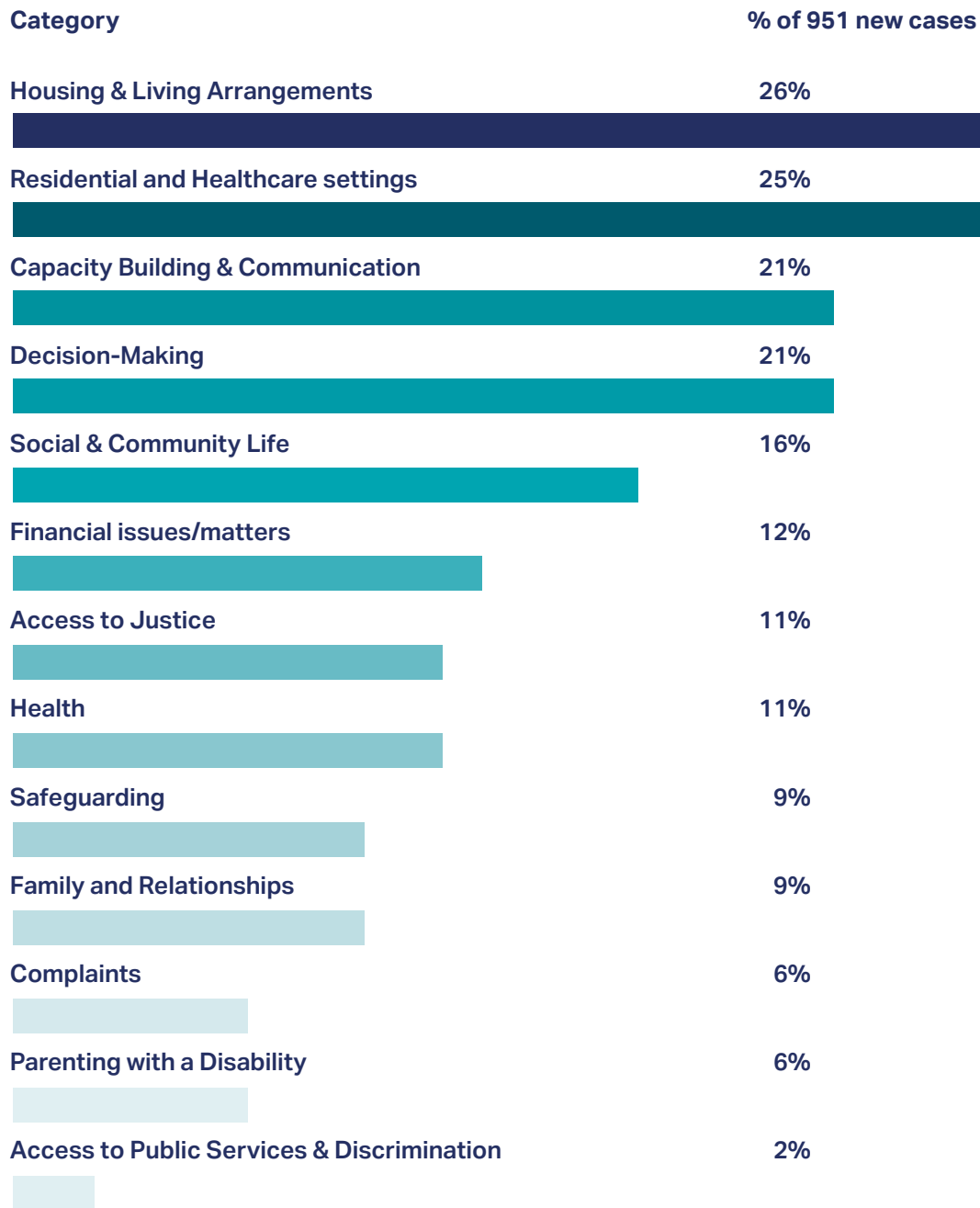
There is an urgent need to overhaul the systemic barriers people with disabilities across Ireland face in accessing their own finances.

Housing was another key issue that arose for people that access NAS services. NAS advocates have worked with people across the spectrum of housing needs. There are some consistent trends that appear across the country that impact the people we advocate for. As mentioned above, these include a lack of accessible and suitable rental accommodation, lack of accessible and suitable social housing, lack of accessible emergency accommodation and difficulties in accessing PA support. This is not an exhaustive list, but just some examples of the types of issues that are reported across the disability sector that are evident in NAS casework.

In 2023, 26% of all cases were related to housing and accommodation-related issues, while 25% of all cases were related to residential and healthcare settings. These are significant figures and represent a large portion of the work of NAS advocates and the needs of people that access our services.

These figures have decreased slightly from previous years: In 2022, 39% of cases were related to housing whereas in 2021, 46% of cases were related to housing. Whilst in 2022, 36% of cases were related to residential and healthcare settings and in 2021 this figure was 43%.

Issue Requiring Support



*Each figure here is independent and represents the total percentage of NAS cases that were linked to the associated issue. For example, 21% of the 1775 cases that NAS advocates worked on in 2023 were related to capacity building.

4.6 Who Engaged with the National Advocacy Service

NAS has a particular remit to provide advocacy services to people in significantly difficult situations. The service worked with a diverse range of people in 2023 who have many different types of disabilities.

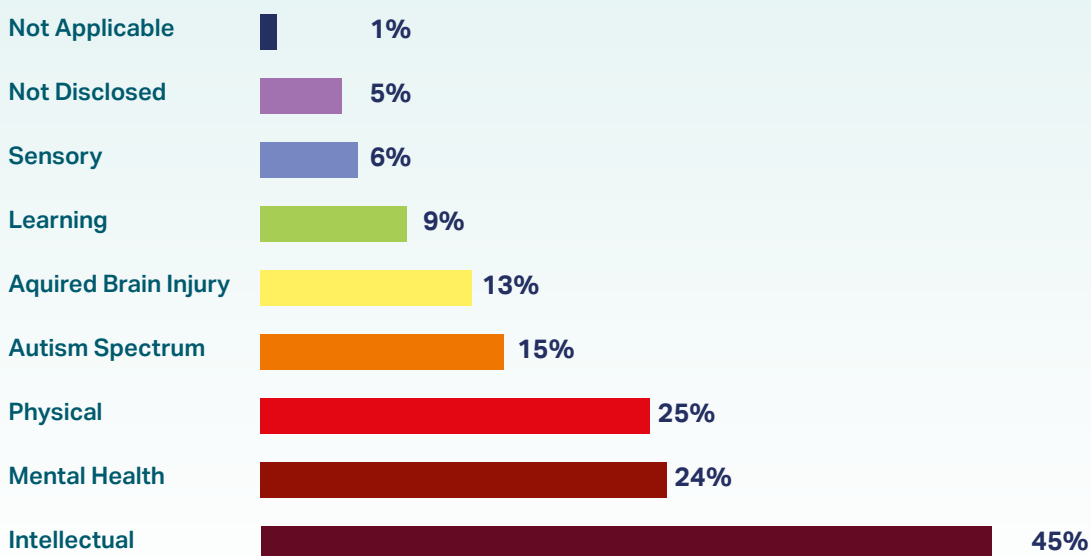
As has been the case for several years, intellectual disability continued to make up the largest cohort of people NAS supports, at 45% of cases. People with intellectual disabilities who engage with NAS are mainly living in residential services or attending day services.

People with physical disabilities also continued to be a significant cohort of those NAS supported in 2023 at 25%. While people with mental health difficulties also feature heavily in NAS casework, with 24% of those NAS supports having some form of mental health difficulty.

The number of people with acquired brain injuries⁷ (ABIs) continues to play a significant role in NAS casework, maintaining the figure of 13% of cases in 2022. This was the same as 2021 and is an increase from the 8 % figure seen in 2019.

A trend which has been continued in NAS service delivery for 2023 is that a significant element of NAS work is with people who have multiple disabilities. For example, a person seeking advocacy may have an intellectual disability and also a physical disability, or mental health issue. Overall, people who have multiple disabilities will often have more complex issues or will experience more difficulty trying to navigate multiple systems of support, which requires them to be provided with a higher level of advocacy input.

Percentage of disability type of people supported by NAS



7. Acquired brain injury (ABI) refers to any damage to the brain that occurred after birth.

Case Study:

Access To Finances

Context:

Jennifer is in her fifties and lives in a residential service. Jennifer is autistic and communicates non-verbally. As a result, she was supported by her service provider to contact NAS via a third-party enquiry form as she wanted to have access to her own finances. Jennifer's family collected her disability allowance each week on her behalf. However, Jennifer only received her money every so often because her family lived in a different county.

Actions by Advocate:

The Advocate agreed an Advocacy plan with Jennifer and they then liaised with the service provider and the HSE Safeguarding & Protection team regarding Jennifer's right to her finances. Jennifer's service provider supported her to develop a proactive strategy to address the issue. They held meetings with Jennifer and her family to discuss plans for Jennifer to have her Disability Allowance paid directly into her own bank account.

Outcome:

With the support of her Advocate, Jennifer was able to gain access to her finances. Jennifer's service provider also supported her to open a bank account and arranged for her family to lodge the Disability Allowance directly into Jennifer's new bank account. As a result of these changes, a plan was also put in place by her Service Provider to develop Jennifer's money management skills.



Case Study:

Quality Of Life And Decision Making

Context:

Adriana is in her forties and had been in an accident which left her with complex medical needs. Although deemed medically fit, she had been living in hospital for a year as there was no suitable accommodation available. Adriana's quality of life deteriorated in hospital and since her first language is not English, it meant she needed a translator to speak to people.

Adriana was unable to move into her family home as she requires full-time care. As her family's first language is not English, they also found it difficult to effectively advocate on her behalf. Although the hospital had applied on her behalf to the HSE disability services for access to a residential placement, she was still waiting.

Actions by Advocate:

Adriana told her Advocate that she wanted to move to an appropriately supported residential placement and not a nursing home. Adriana was fully assisted during all discussions with her Advocate by a translator. This allowed her to express her wishes and gain an understanding of how NAS independent advocacy works. She wanted to know what her options were and asked for an update on her application to the HSE Disability Services, which she had submitted 10 months earlier. Since then, neither the hospital nor her family had heard anything back.

During the meeting, an advocacy strategy was developed and agreed. Adriana asked her Advocate to contact the HSE to find out the status of her application and arrange a meeting with her and her family, as it was her wish to include them in the process. The Advocate contacted the HSE on Adriana's behalf and sought an update on her application for a residential place.

The Advocate was able to emphasise to the HSE Disability Services that the amount of time Adriana had spent in hospital was unacceptable to her and that her will and preference was to live in an appropriate community-based placement.

Outcome:

After a series of engagements between Adriana, her Advocate and the HSE disability services, an appropriate community-based residential placement was identified for her to move to from the hospital. She is now living in a setting where she can live a life of her choosing to the fullest extent possible.



5. Our Policy Work

5.1 Stakeholder engagement

Engagement with external statutory bodies:

NAS experience and expertise means the service has contributed to a wide range of statutory bodies, public debates and discussion, key stakeholder meetings, and organisational working groups and forums. NAS has provided insights into the role of advocacy and the importance of ensuring that a person's will and preference, voice and experience, are central components in policy discussions.

NAS has continued to build strong working relationships with our funding organisation CIB, the HSE National Human Rights and Equality Policy Office and National Quality Improvement Division, HIQA, the Court Service of Ireland, the HSE Open Disclosure Office, the Joint Oireachtas Committee on Disability Matters, the Department of Health, the Department of Justice, the Department of Social Protection, the Department of Children, Equality, Disability, Integration & Youth, IHREC and the Decision Support Service. Some examples of our engagement with external bodies include:

- Appearance before the Joint Oireachtas Committee on Disability matters – Awareness raising, lived experience of congregated settings. (February 9, 2023)
- Presentations to a wide range of external stakeholders including: The HSE Human Rights and Equality office, Department of Social Protection Staff, The Mental Health Commission, The Mental Health Tribunal panel, The Central Bank's Consumer Advisory Group (CAG), HSE Staff, Judicial Council, Legal Aid Board External Consultative Meeting and HSE ADM Transitional Oversight Group.
- Collaboration on potential research proposal with Professor Martin McMahon, TCD School of Nursing on People with Intellectual Disabilities and timely access to cancer diagnosis.
- Engagement with a wide range of key stakeholders, including meetings with: The Decision Support Service, Office of the Ombudsman, The Banking and Payments Federation of Ireland, The Central Bank, Tusla, The Irish Human Rights and Equality Commission (IHREC), HIQA, Dept. of Health - Protection of Liberty Safeguards Expert Advisory Group, ADM Transitional Oversight meeting, Legal Aid Board, Immigrant Council of Ireland, Minister Butler regarding the Nursing Home Expert panel report progress, The HSE Human Rights and Equality office, The HIQA Older Persons team, the Court Service, The Mental Health Commission and the National Care Experience Programme.

- Interviews for various research projects, including the following: interview with Dr. Charles O'Mahony, University of Galway, for IHREC-funded research into Article 13 UNCRPD Access to Justice; interview with The HSE Sharing The Vision Recommendation under 65 Gap Analysis Researcher on NAS advocacy in Mental health settings; interview by Dr. Jennifer Okeke, Immigrant Council of Ireland, for the EASY project to enhance support for victims/survivors of forced marriage; interview with a researcher in The University of Limerick on Do Not attempt CPR orders for The HSE National Office for Human Rights and Equality Policy.
- Working with the Department of Children, Equality, Disability, Integration and Youth on how NAS can support those who may access the new mother and baby Institutions payment scheme.
- Input to a HIQA Focus Group towards the development of a tool for the self-assessment of Standards for all Health and Social Care settings.
- Continued work with the Court Service of Ireland through input to the Court modernisation programme. Advocates and management also assisted the Court Service Civil Reform in the review of content and website testing for information on Debt and Assisted Decision-Making issues.
- Attendance at various national events, some of which include: The National Disability Consultative Forum, Mental Health Commission Annual seminar, Department of Justice Family Justice Development Forum, DSS launch of public awareness campaign, IHREC Legal Service Seminar, the ADM and Finance Banking Roundtable event, The Nursing Home Ireland Excellence in Care Awards, The International Safeguarding Conference and The National Patient Safety Office Conference to name a few.



NAS National Manager - Joanne Condon providing evidence to Joint Committee on Disability Matters

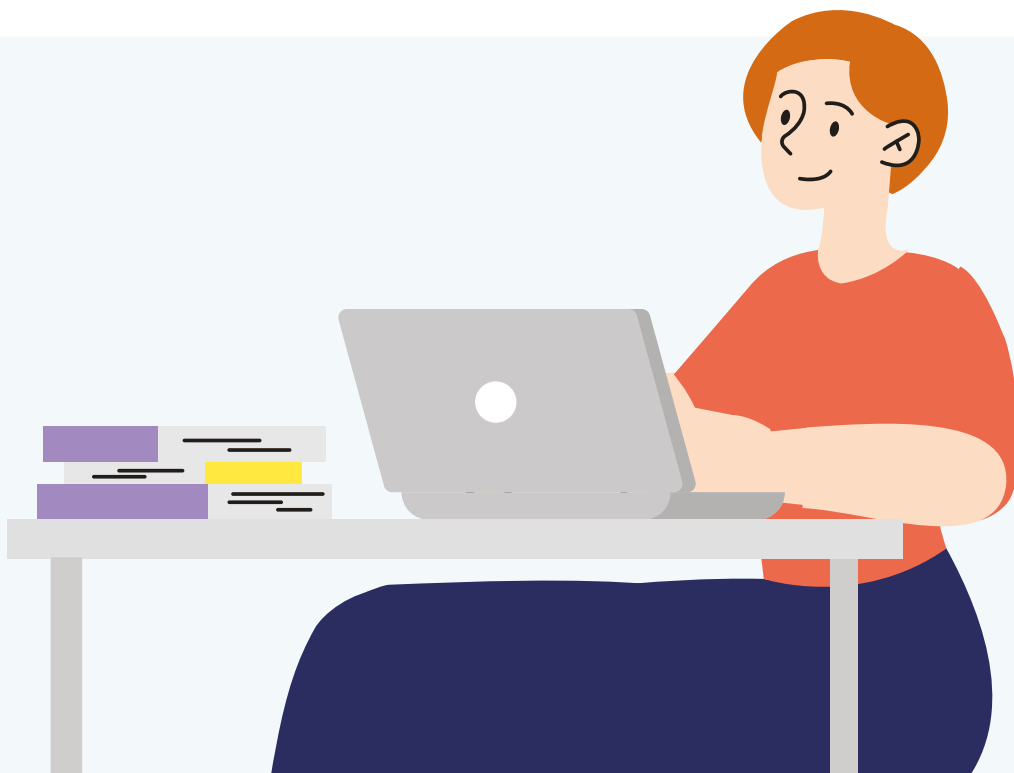
Membership of the following groups:

- National Care Experience Programme Steering Group
- Department of Health Protection of Liberty Safeguarding Expert Advisory Group
- HSE ADM Transitional Oversight Group
- HSE ADM Implementation Steering Group
- HSE Under 65 Stakeholder Reference Group and Steering group
- Ward of Court Research Advisory Group.
- Women's Aid advisory group on Intimate Partner Violence and Disabled Women Research Project.
- HSE National Disability Consultative Forum
- NWIHP Clinical Advisory Group and Clinical Guidelines Group
- Safeguarding Ireland Advisory Committee
- Dept of Justice Family Advisory group
- National Consultative Committee
- International Advocacy Network (Ireland, Finland, New Zealand, Northern Ireland, South Korea, Australia, UK).
- Court Service Civil Society Forum: Modernisation Programme advisory group



5.2 Public Consultations and Submissions

- NAS Report to Ombudsman on “Wasted Lives” progress report.
- Department of Justice: Civil Legal Aid Review Submission (February 2023)
- Department Of Justice Consultation: Questionnaire on Operating Model Review (April 2023)
- Programme for Government: Pre-Budget Submission (June 2023)
- National Disability Authority consultation: Draft Code of Practice on Accessible Public Buildings.
- The HSE National Office for Human Rights and Equality written submission: Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) policy and practice.
- NAS were successful in a social policy grant application to CIB to produce a social policy report on the issue of access to finances for people with disabilities.
- NAS is a member of a newly established international advocacy leaders’ network, providing an exciting opportunity to network and learn from worldwide experts in the field of advocacy including countries like the UK, Canada, Finland, Australia, New Zealand and South Korea.



6. Raising Awareness of Our Service

“NAS provided information which was very impactful in progressing access to urgent health treatment for a person where rights were previously being restricted. Thank-you for your suggestions and input, as well as your support in upholding their rights.”

A Service Manager who worked closely with a NAS Advocate supporting a person in their service in 2023

6.1 Promoting the National Advocacy Service

In 2023, NAS Advocates, Senior Advocates and Regional Managers took part in 198 outreach events. This included large scale stakeholder events such as The International Safeguarding Conference, as well as online presentations like the HSE Webinar on Getting Ready for Advance Healthcare Directives under the ADM Act, and meetings with groups in disability services, hospitals, residential centres, and day centres. NAS staff presented to people with disabilities who could potentially use the NAS service, and to staff and other stakeholders amongst whom an increased awareness and understanding of the service led to increased enquiries

“NAS advocates kindly gave a presentation to individuals living in one of our designated centres. This presentation was very informative, and individuals noted how much they enjoyed and learned from this experience.”

Email from service provider following a NAS promotional presentation

Communicating our message



The NAS website received 29,355 individual visits by 8,099 unique users. This has more than doubled since the previous year.

NAS increased its use of social media in 2023:



The Service's Facebook page grew from 2,066 followers at the end of 2022 to 2,286 at the end of 2023, an increase of 10 %.



The Service's Twitter Page grew from 2,009 followers at the start of 2023 to 2,232 at the end of 2023.



The Service's LinkedIn grew from 879 followers at the end of 2022 to 4,848 at the end of the year.



NAS ran an ADM Social Media awareness campaign from April 26th – May 4th. The campaign illustrated the impact of the ADM on people seeking NAS advocacy. It was highly successful with almost 30,000 impressions over nine days and lots of positive engagement from stakeholders. This is one of the highest ever social media engagements in NAS's history to date.



The NAS/PAS 2022 Annual Report was launched on July 31st and was well received. There was also a social media campaign alongside four case example videos. The report received coverage in numerous media outlets.



NAS was invited to speak on several radio shows in 2023 and our National Manager was interviewed by several national papers to promote the service, the issues faced by those NAS supports, and detail how people can contact NAS.

"Your Advocates worked tirelessly to help my brother and I access the right information and support always showing the utmost respect by informing me of their efforts and plans. Both advocates were always available to speak to me even through the pandemic. They were both patient and kind. I wouldn't be half the advocate today for my brother without their scaffolding. They supported me and my brother and built my confidence/strength to advocate, they really listened to my views and took action on them. We are really thankful to the Advocates and NAS for the lengthy role you played in our lives. Thank you."

Email from a person who accessed NAS service



NAS is funded & supported by the
Citizens Information Board



The Patient Advocacy Service is funded and
supported by the Department of Health



An Roinn Sláinte
Department of Health

**National Advocacy Service (NAS) for People with Disabilities
& Patient Advocacy Service**

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